



BIOGRID
AUSTRALIA
Health through information



***has climbed the biomedical informatics
“Stairway to Heaven”***



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Biomedical Informatics Stairway to Heaven

1. Interested but “not ready”
2. Identify Databases and Clinical Champions
3. Develop data items, forms and document specifics
4. Database development
5. Frontend application - selection / development
6. Data entry / cleaning
7. Extract Transform Load to Local Research Repository
8. Virtual Private Network & Federated Data Integrator
9. Unique Subject Identification generation
10. Testing data linkage processes
11. Users have full access
12. Users are trained
13. Database annotation for business glossary
14. Develop standard reporting

Stairway to Heaven Climbed for:

- ✓ Colorectal
- ✓ Brain
- ✓ Breast
- ✓ Sarcoma
- ✓ Lung
- ✓ Head & Neck
- ☐ Rare Cancers

Agenda

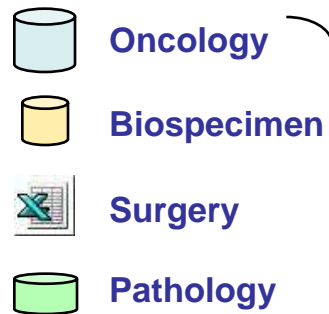
- **Aggregation**
- **Information**
- **Portals**
- **Resources**



Aggregation - Model

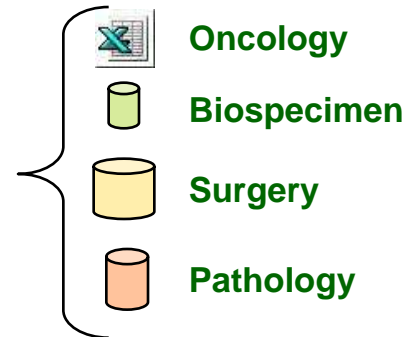
Problem

Hospital A



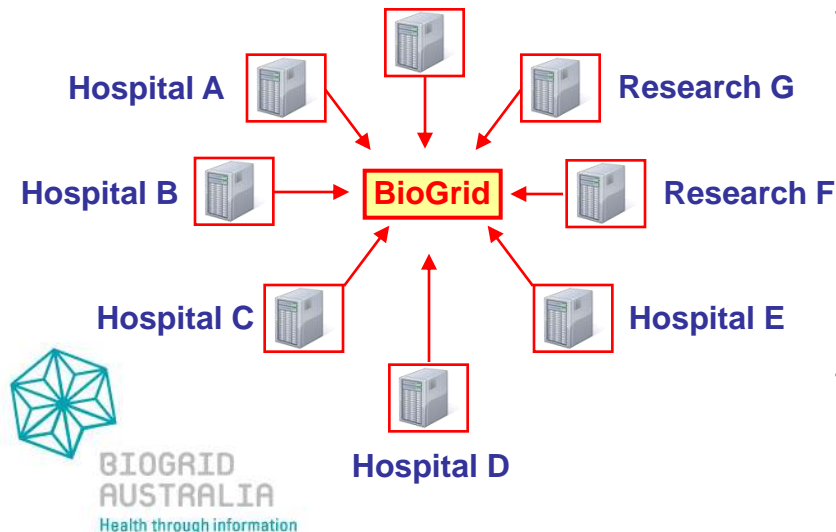
- ⊗ inconsistent access control
- ⊗ inconsistent ethics approval
- ⊗ uncontrolled sensitive data
- ⊗ limited use of data
- ⊗ difficult to merge data

Hospital B



Solution

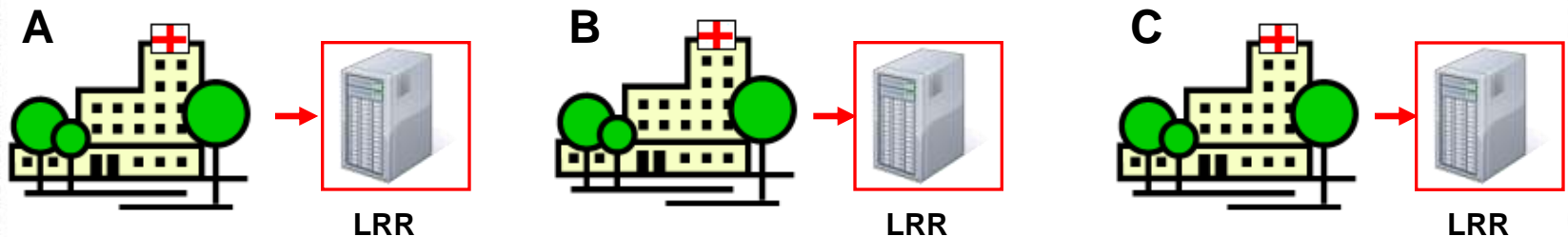
Government Data



- ✓ single access control
- ✓ single ethics approval
- ✓ de-identified data
- ✓ multiple sources of data
- ✓ uniformly formatted data

Aggregation & Privacy

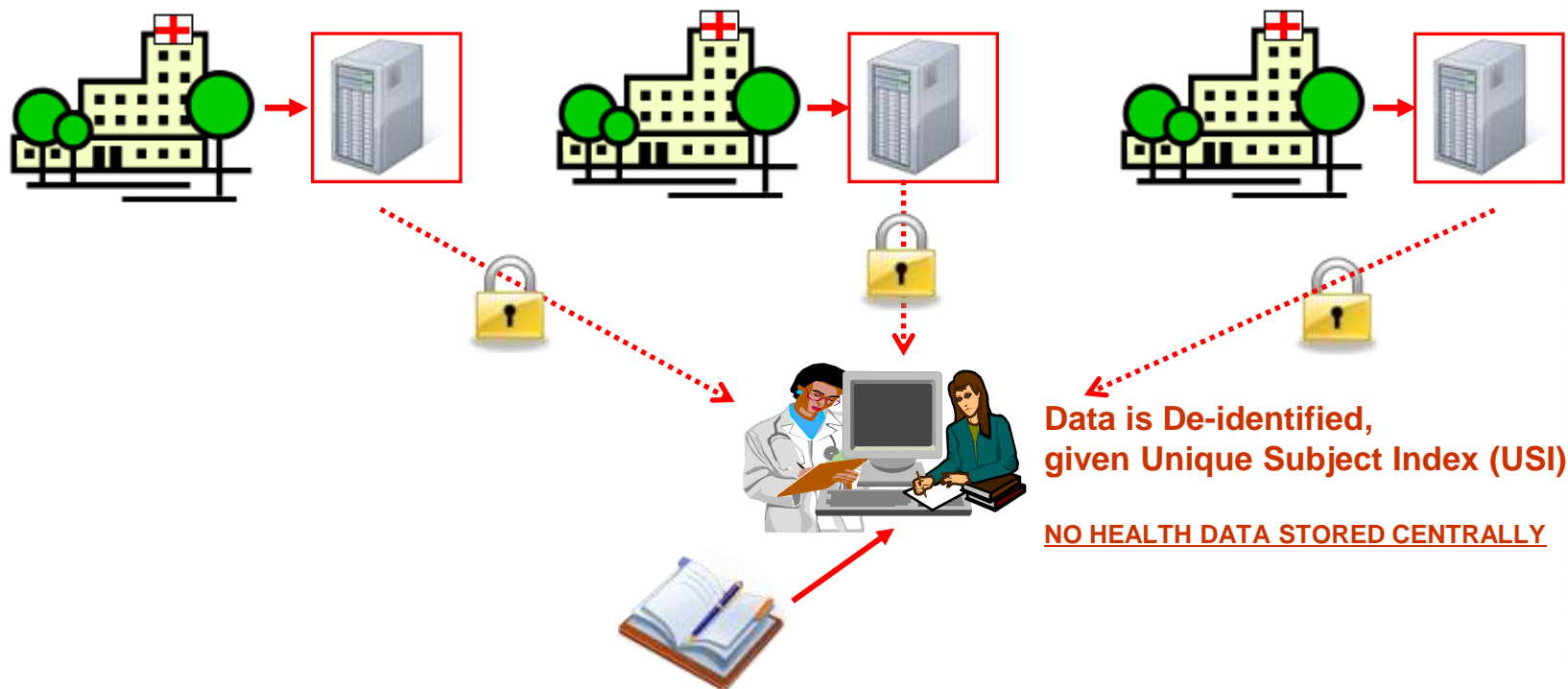
1. BioGrid imports local data into a local server (“Local Research Repository” LRR)



2. On each LRR server, data is processed to remove patient identity and given Unique Subject Index (USI)

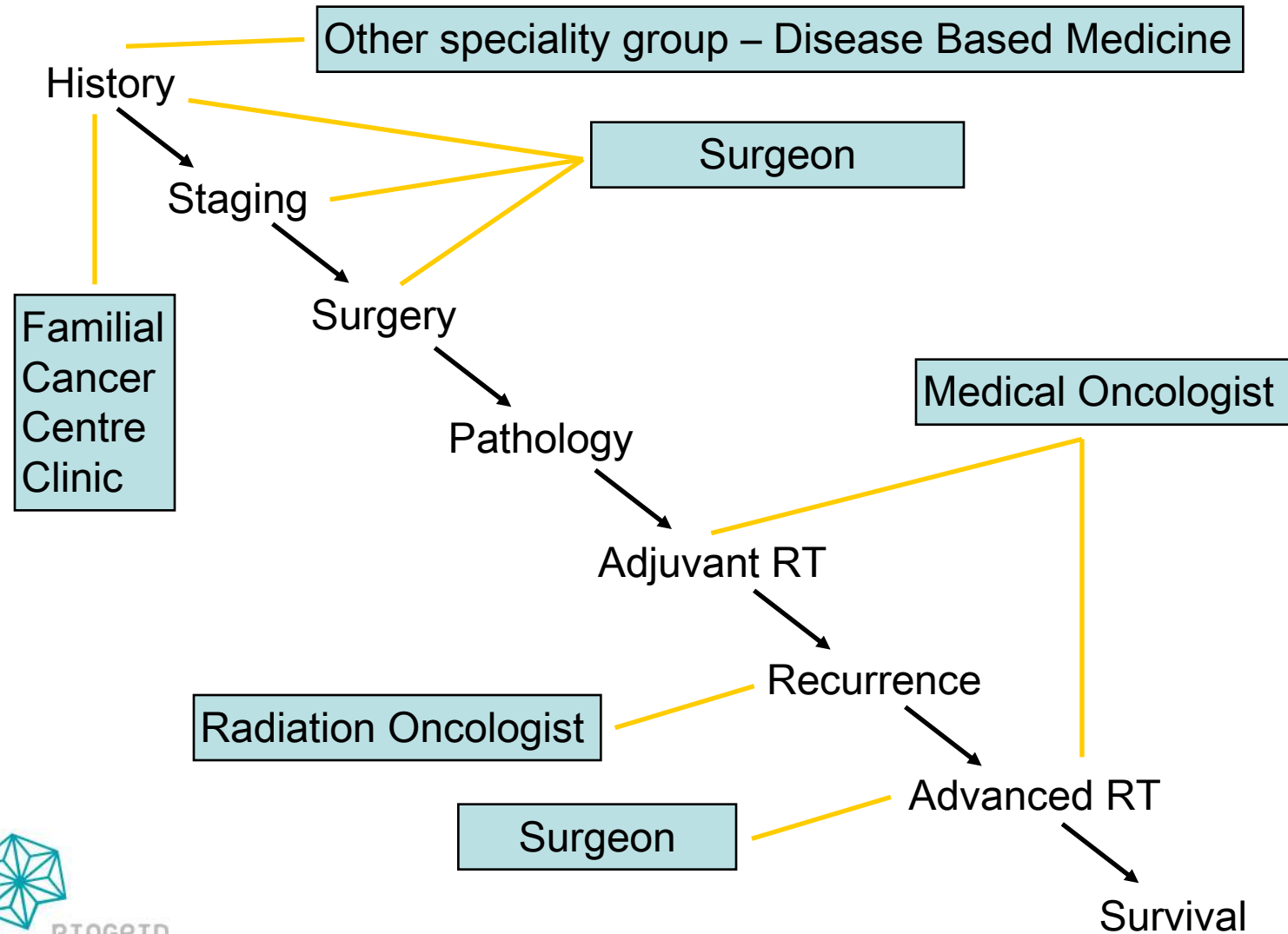
Aggregation & Connecting Data

3. BioGrid establishes a secure connection from LRR to Central Server



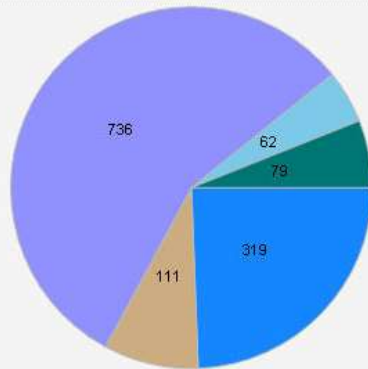
4. BioGrid monitors and logs all access and use of linked data

Information



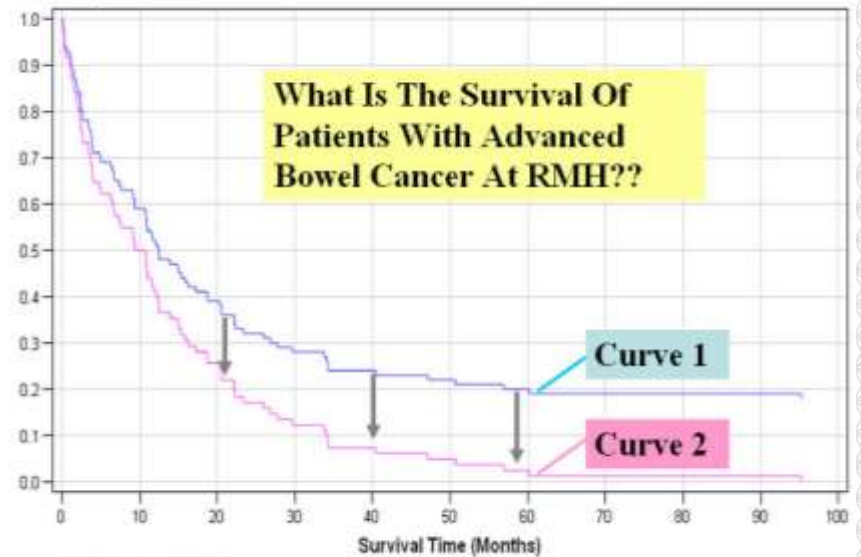
Colorectal Cancer

Primary Procedure (Colon)



■ Right Hemicolectomy ■ Sub total colectomy
■ Extended Right Hemicolectomy ■ Left Hemicolectomy
■ Other

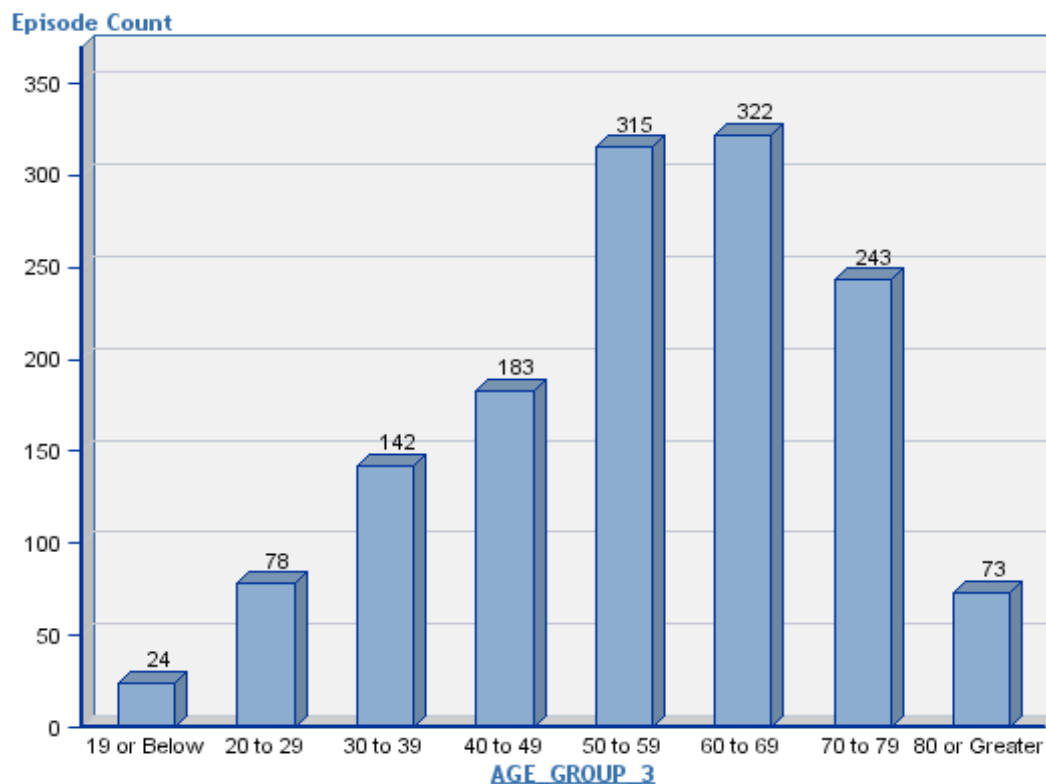
Probability of Survival



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Brain Cancer

Age breakdown of brain tumour patients seen

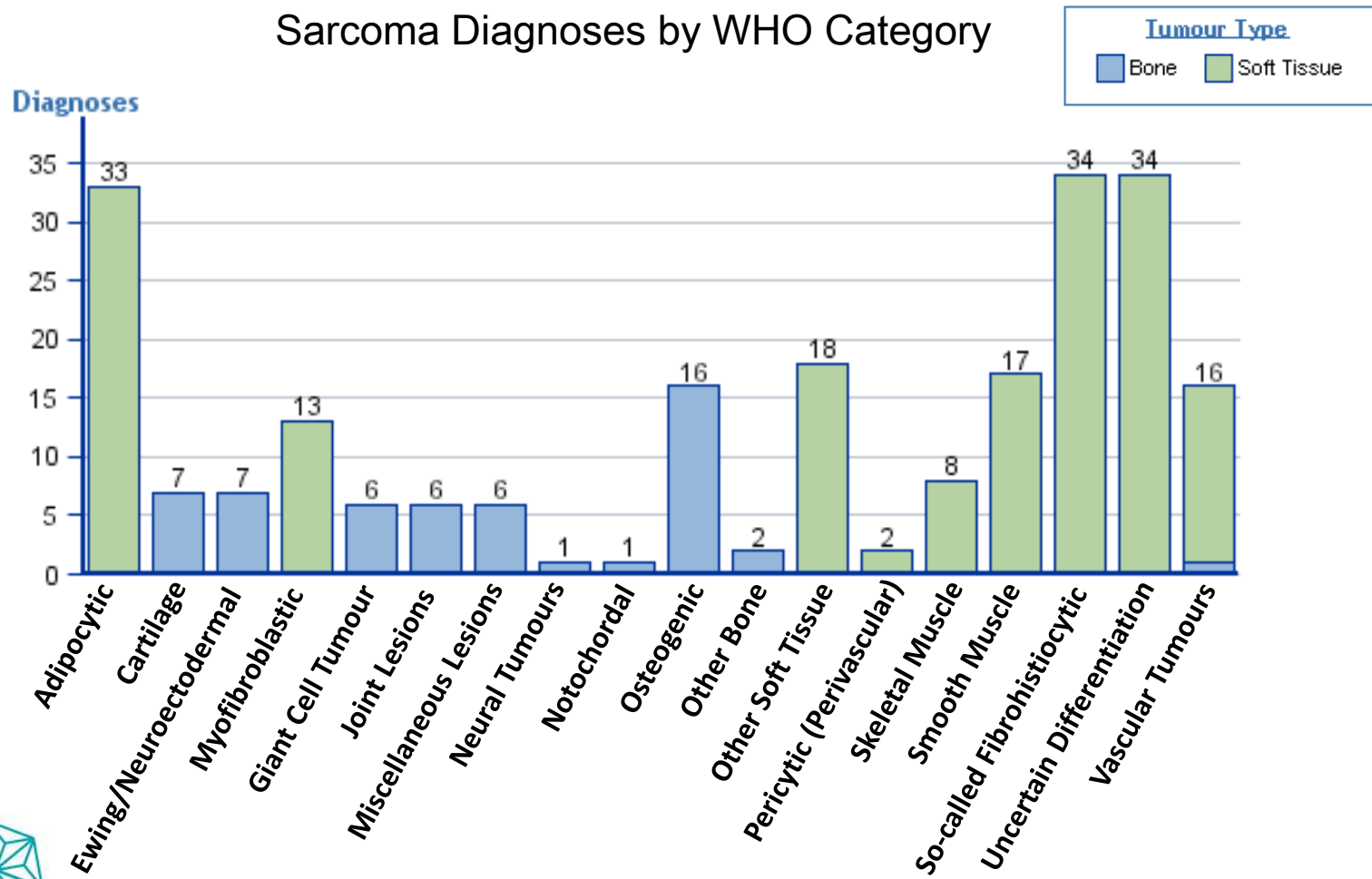


Total 1380. 316 (23%) are >70 years old. 244 (18%) are <40 years old.



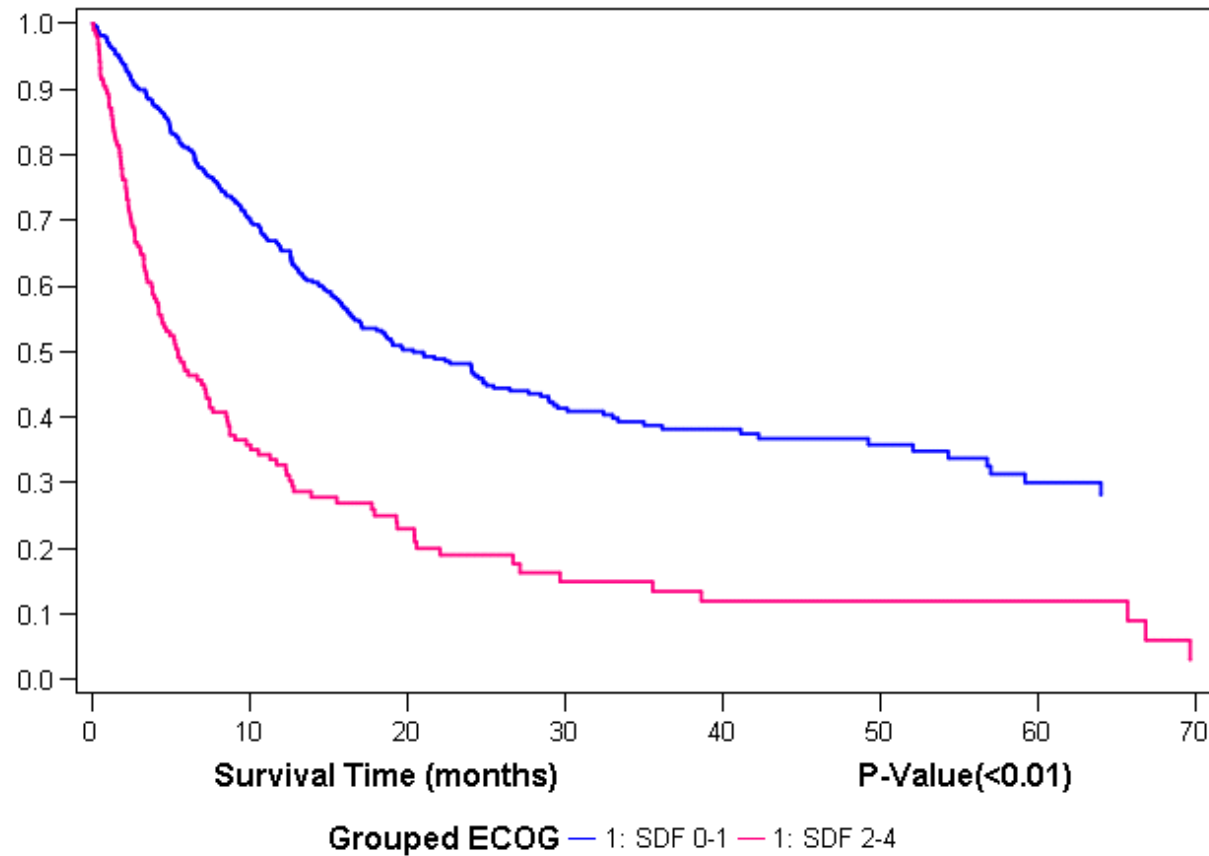
Sarcoma

Sarcoma Diagnoses by WHO Category



Lung Cancer

Lung Patients By ECOG



Portal - BioGrid Australia Website

The screenshot shows the BioGrid Australia website interface. At the top is a navigation bar with links: Home, About Us, Research, Governance, Data Information, Get Access, Data linkage, and Analysis Tools. A 'Log In' button is in the top right corner. Below the navigation bar is a search bar with a 'Search' button. The main content area features a welcome message, a video player (labeled 'YouTube html embedded'), and a section for 'BioGrid Australia - Health through information'. To the right of the main content is a 'Quick Links' section with links to ACCORD, Apply for access, Grant Quote Request, and SAS Training. Below this is a 'BioGrid's current research areas' section with a list of categories: Endocrinology, Images, Neurosciences, Oncology, and Other. The 'Oncology' category is expanded, showing a list of cancer types. At the bottom of the main content area is a 'BioGrid Event Calendar' table.

Annotations:

- Themes and skins:** Points to the top navigation bar and the 'Log In' button.
- Search Component:** Points to the search bar.
- Menu Component:** Points to the 'Quick Links' section.
- Navigator Component:** Points to the 'BioGrid's current research areas' section.
- Menu Component:** Points to the 'Oncology' category list.
- Menu Component:** Points to the 'Other' category list.
- Themes and skins:** Points to the bottom navigation bar.

BioGrid Event Calendar:

Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar
17/04/2009	SAS Training 17 April										
30/04/2009	SAS Training 30 April										

Themes and skins

Search Component

Menu Component

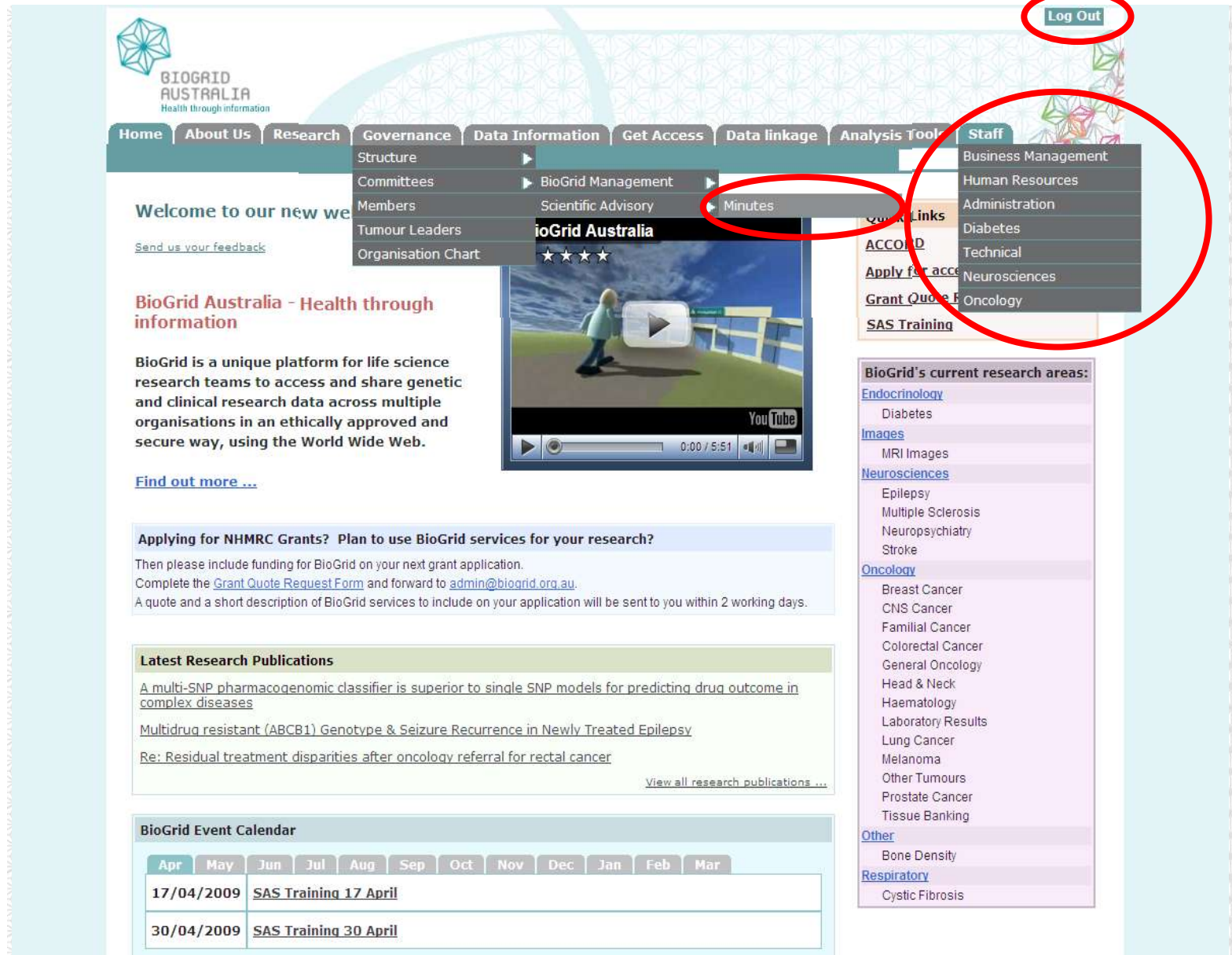
Navigator Component

Menu Component

Menu Component

Themes and skins

Accessibilities by different user groups



BIOGRID AUSTRALIA
Health through information

Home About Us Research Governance Data Information Get Access Data linkage Analysis Tools **Staff**

Welcome to our new website
[Send us your feedback](#)

BioGrid Australia - Health through information

BioGrid is a unique platform for life science research teams to access and share genetic and clinical research data across multiple organisations in an ethically approved and secure way, using the World Wide Web.

[Find out more ...](#)

Applying for NHMRC Grants? Plan to use BioGrid services for your research?

Then please include funding for BioGrid on your next grant application.
Complete the [Grant Quote Request Form](#) and forward to admin@biogrid.org.au.
A quote and a short description of BioGrid services to include on your application will be sent to you within 2 working days.

Latest Research Publications

[A multi-SNP pharmacogenomic classifier is superior to single SNP models for predicting drug outcome in complex diseases](#)

[Multidrug resistant \(ABCB1\) Genotype & Seizure Recurrence in Newly Treated Epilepsy](#)

[Re: Residual treatment disparities after oncology referral for rectal cancer](#)

[View all research publications ...](#)

BioGrid Event Calendar

Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar
17/04/2009	SAS Training 17 April										
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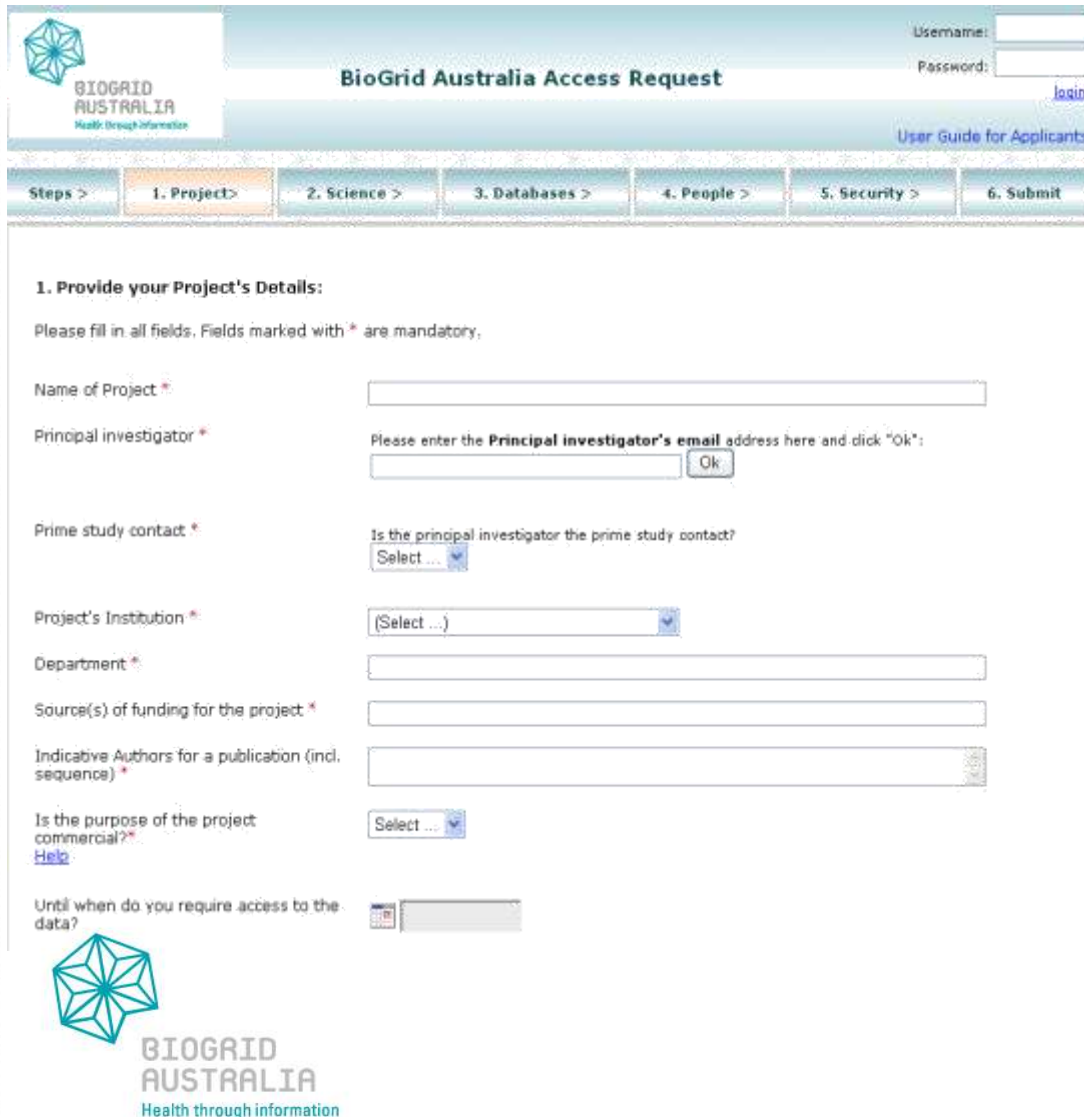
Staff

- Business Management
- Human Resources
- Administration
- Diabetes
- Technical
- Neurosciences
- Oncology

BioGrid's current research areas:

- [Endocrinology](#)
 - Diabetes
- [Images](#)
 - MRI Images
- [Neurosciences](#)
 - Epilepsy
 - Multiple Sclerosis
 - Neuropsychiatry
 - Stroke
- [Oncology](#)
 - Breast Cancer
 - CNS Cancer
 - Familial Cancer
 - Colorectal Cancer
 - General Oncology
 - Head & Neck
 - Haematology
 - Laboratory Results
 - Lung Cancer
 - Melanoma
 - Other Tumours
 - Prostate Cancer
 - Tissue Banking
- [Other](#)
 - Bone Density
- [Respiratory](#)
 - Cystic Fibrosis

Portal – Access to Data



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BioGrid Australia Access Request

Username:
Password: [login](#)
[User Guide for Applicants](#)

Steps > **1. Project >** 2. Science > 3. Databases > 4. People > 5. Security > 6. Submit

1. Provide your Project's Details:

Please fill in all fields. Fields marked with * are mandatory.

Name of Project *

Principal investigator * Please enter the **Principal investigator's email** address here and click "Ok":

Prime study contact * Is the principal investigator the prime study contact?

Project's Institution * (Select ...)

Department *

Source(s) of funding for the project *

Indicative Authors for a publication (incl. sequence) *

Is the purpose of the project commercial? * [Help](#)

Until when do you require access to the data?

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First step by researcher

Researcher request:

- 1 ? Data required,
- ? Science of project,
- ? Agree to terms & conditions

steps by BioGrid

Custodian Authorisation:

Approve;

- 2 ✓ Data requested for the project
- ✓ Assess the science

Management & Scientific Advisory Committees

Approve;

- 3 ✓ Data requested
- ✓ The project
- ✓ The researcher

Ethics Committee:

Note decision and keeps files for inspection

Report all queries on the system:

- 5 ➤ To Management Committee
- To Ethics committees as required.
- To data custodians as required.

SAS Web Report Studio

The screenshot shows a web browser window titled "SAS Web Report Studio : Welcome to SAS Web Report Studio - Windows Internet Explorer". The address bar displays the URL "http://mmimsas.ssg.org.au/SASWebReportStudio/webreportstudio.jsp". The browser's menu bar includes "File", "Edit", "View", "Favorites", "Tools", and "Help". The toolbar shows a search bar with "Google" and various navigation icons. The page header features the "SAS Web Report Studio" title and the SAS logo. Below the header, a yellow banner reads "Welcome to SAS Web Report Studio" with a "How Do I?" link. The main content area contains a welcome message: "SAS Web Report Studio lets you create, view, and save reports from your Web browser. Enter your user name and password to log on to SAS Web Report Studio." Below this message is a login form with two input fields: "User name:" and "Password:". A "Log On" button is positioned below the password field. At the bottom left of the page, the copyright notice "Copyright© 2006 by SAS Institute Inc., Cary, NC USA. All Rights Reserved." is visible. The browser's status bar at the bottom shows "Done", "Local intranet", and a zoom level of "100%".

SAS Web Report Studio : Welcome to SAS Web Report Studio - Windows Internet Explorer

http://mmimsas.ssg.org.au/SASWebReportStudio/webreportstudio.jsp

File Edit View Favorites Tools Help

SAS Web Report Studio : Welcome to SAS ...

SAS Web Report Studio

Welcome to SAS Web Report Studio

How Do I?

SAS Web Report Studio lets you create, view, and save reports from your Web browser.
Enter your user name and password to log on to SAS Web Report Studio.

User name:


Password:

Log On

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Done Local intranet 100%

IBM InfoSphere Business Glossary



**BIOGRID
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Log In

Home

• Search • Category Tree • Stewards • About • Help • Log Out

Search

Basic | Advanced ?

Find: ☒ Terms ☒ Categories ☐ IT Assets

☐ Name Begins With

Site Map | Terms & Conditions

[New Patient](#) [Search](#) [Clinic Lists](#) [Settings](#) [Logout](#)

Name: Test, Patient .

ID: 4533

- New Episodes
 - Colorectal
 - Brain
- Patient Details
 - Colorectal 1/01/1900
 - Preoperative Data**
 - Operation Report
 - Surgery Outcomes
 - Adjuvant Therapy
 - Pathology
 - Appx
 - Followup
 - Summary

Colorectal Episode

UR No: 25525 Campus MH Date of Diagnosis 01/01/1900

ECOG 0 Consultant Gibbs, Peter

[Referral](#)

Presentation Pathway

Cancer History

Past History of other cancer(s) No

Family Hx of CRC Yes

No. of 1st degree relatives 90

Age at each incidence 67

Comorbidities

Diabetes Yes

Type Type 2

Hx of Smoking No

Crohns Disease No

Ulcerative Colitis No

Presentation

Presentation Symptomatic Commonwealth FOBT trial Yes

Preoperative Investigations

CEA Yes Result 0.9

Endorectal US No

MRI No

Chest CT Yes Distant Disease No

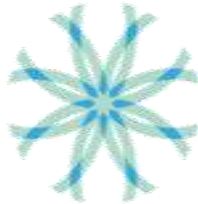
Abdo CT No

CXR No

PET No

Height(cm) 190 Weight(kg) 93

Surgery



CART-WHEEL
Center for Analysis of Rare Tumors

CART-WHEEL

Center for Analysis of Rare Tumors

[Home](#) [Patients](#) [Patient Proxy](#) [Health Professionals](#) [Research](#) [Support](#) [Contact](#)

Have you been diagnosed with a rare tumor or a [rare type of a more common tumor](#)?

Although your particular tumor type occurs rarely, when all the different kinds of 'rare tumors' are taken together they make up 20% of all cancers diagnosed. Despite this, as a group, they only receive about 5% of research funding and attention.

Login

Part of the problem is that researchers cannot find enough cases of each tumor type to study to make the progress needed to find better treatments and provide more information about your disease.

Register

Through CART-WHEEL we are inviting people from all over the world to submit information about their particular tumor so that researchers can develop new insights into these understudied rare tumors.

CART-WHEEL Principal Investigator:

Dr Clare L Scott, Physician Scientist and Medical Oncologist MBBS PhD FRACP [Melbourne Health HREC](#)

Our Mission

How does it work?

Get involved

FAQ

BioGrid Australia

Dedication

Our Mission

CART-WHEEL is the **Center for Analysis of Rare Tumors** but also means ...

Collect information from as many people as possible

Analyse the information about rare tumors

Research new discoveries for rare tumors

Treat rare tumors more effectively

Through CART-WHEEL we are inviting people from all over the world to submit information about their particular tumor so that researchers can develop new insights into these understudied rare diseases.

WE NEED YOUR HELP to keep CART-WHEEL in motion.





CART-WHEEL

Center for Analysis of Rare Tumors

CART-WHEEL
Center for Analysis of Rare Tumors

[Home](#) **[Patients](#)**

[Patient Proxy](#)

[Health Professionals](#)

[Research](#)

[Support](#)

[Contact](#)

Participant and Information Consent - FAQ

Download: [Participant Information Consent Form](#) (Word document 70KB)

Download: [Patient Proxy - Participant Information Consent Form](#) (Word document 78KB)

4 Levels of Consent

- 1.Data to be used in a re-identifiable way
- 2.Contact for up-date of personal information
- 3.Contact for pathology or medical record
- 4.Contact for involvement in research study or clinical trial

In Summary

Current

- Biomedical informatics across all cancer tumour streams
- + three other disease groups - diabetes, neuroscience, respiratory
- 21 members representing 37 institutions across 4 states and territories
- 180,000+ identity protected patients

Ongoing development

- Climbing the Stairway to Heaven
 - **Thyroid**
 - **Pituitary**
 - **Melanoma**
 - **Upper GI**
 - **Prostate**
 - **Gynaecology**
 - **Renal**

